



**Sarcoma
Patients
EuroNet**

*Together We Can Make A Difference
For Those Affected By Sarcomas!*



PAWS-GIST clinic (Paediatric Adolescent Wild-type and Syndromic GIST)

The PAWS-GIST clinic is one element of a programme of work that we initiated, with the objective of improving treatment and finding a cure for PAWS-GIST cancer. The clinic provides patients with individual consultations with a multidisciplinary team of GIST specialists. The clinic team review patient's medical history, previous treatment, scan and histopathology results (where available) and conduct additional genetic analysis and further tests in order to provide patients with the most appropriate treatment plan for their individual circumstances. The clinic team is actively seeking treatment options that can be effective for this rare subgroup of GIST patients and is working to open opportunities for PAWS-GIST specific clinical trials.

The clinic provides the opportunity for patients to meet others living with this rare subset of GIST cancer. The charity covers travel and accommodation expenses for patients and family members to attend the clinic, and a welcome meal the night before so that they can get to know each other in an informal environment.

The target group for the PAWS-GIST clinic are patients with 'Wild-type' GIST, who have no KIT or PDGFRA mutations.

Our first clinic was held in April 2014, after four years of raising the required funds to open the clinic. The project is ongoing and we hold the clinic three times a year (with the next clinic being held on 7th December 2018).

We required funds to initiate and cover the costs of the clinic. These have been (and continue to be) raised by fundraising efforts of numerous supporters. Due to increased awareness of the clinic, we are receiving more requests from patients to attend. We would like to increase the number of clinics held per year to four and will require additional funds to do so.

To date we have held 13 clinics and over 70 individual patients have benefited from attending (some patients have attended more than once). The clinic has connected researchers and lead several research publications, including featuring in the UK clinical practice guidelines for the management of GIST (see Judson et al, 2017).

There is much more work to be done but the infrastructure is now in place to help PAWS-GIST patients both now and in the future. We have recently formed a consortium with American and European specialists, focusing on SDH deficient GIST as yet another development of the PAWS-GIST clinic.

More information and clinic reports are available on our website www.pawsgistclinic.org.uk

Additional value of your project for the sarcoma population

The PAWS-GIST clinic raises awareness of sarcoma, particularly GIST. Diagnosis, treatment and care of sarcoma patients is complex and best handled by a team of expert specialists. The PAWS-GIST clinic multi-disciplinary team are connecting with specialists worldwide to tackle the unmet needs of this incredibly rare patient group. The clinic provides a template example of how to gather data and stimulate research into rare cancers such as sarcoma. Resulting clinical trials and research could be of wider benefit to other GIST patients (with KIT and PDGFRA mutations) as well as other rare cancer groups with similar biologies. The clinic highlights the need for, and benefits of specialist multidisciplinary treatment of sarcoma cancers (e.g. specialist oncology, geneticists and pathologists).



GIST Support UK / PAWS GIST